

# Patient Perceptions of Arm Care and Exercise Advice After Breast Cancer Surgery

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**E**arly detection and advances in breast cancer treatment have resulted in an increasing number of survivors since 1990 (American Cancer Society, 2009). Emphasis is placed on minimizing long-term side effects of treatment to facilitate survivors' return to healthy lives. However, myriad chronic upper limb impairments that result from surgery and radiotherapy (e.g., shoulder restriction, pain, lymphedema) may interfere with some women's ability to resume normal physical function (Carter, 1997; Fu, 2005; Hack, Cohen, Katz, Robson, & Goss, 1999; McNeely et al., 2006; Satariano, Ragheb, Branch, & Swanson, 1990). Chronic impairments such as lymphedema also may contribute to poor psychological health, resulting in low self-esteem and poor body image (Carter; Hull, 2000; Tobin, Lacey, Meyer, & Mortimer, 1993).

Advice concerning arm care and exercise after breast cancer surgery aims to prevent the development of chronic upper limb symptoms. Conflicting advice has been reported about the extent to which women may use their affected arm after surgery (Collins, Nash, Round, & Newman, 2004; Greenslade & House, 2006; Karki, Simonen, Malkia, & Selfe, 2004). The most common differences in advice appear to be between traditional advice, in which women are instructed to minimize the risk of lymphedema by avoiding strenuous arm work, and advice based on current research, which supports normal use of the affected arm (Ahmed, Thomas, Yee, & Schmitz, 2006; Kilbreath, Refshauge, Beith, & Lee, 2006; McKenzie & Kalda, 2003; Ohira, Schmitz, Ahmed, & Yee, 2006). The National Lymphedema Network (2008a, 2008b) updated its position statement about risk-reduction practices and exercise so that women are no longer advised to avoid strenuous activity, such as lifting heavy objects (Ridner, 2002).

Many complex factors affect how women interpret advice given by health professionals about arm care and exercise. Contributing factors include personality, demographic and treatment variables, and internal perceptions of threat and coping (Ajzen, 1991; Becker, 1974; Rogers, 1983). Protection Motivation Theory (Rog-

**Purpose/Objectives:** To describe in greater detail women's experiences receiving advice about arm care and exercise after breast cancer treatment.

**Design:** Cross-sectional survey.

**Setting:** Three hospitals in Sydney, Australia.

**Sample:** 175 patients with breast cancer recruited 6–15 months after their surgery.

**Methods:** Patients completed a survey about their perceptions of arm activity after breast cancer and were asked to respond to an open-ended question about their experience receiving advice about arm care and exercise. Comments from 48 women (27%) who volunteered responses were collated and categorized.

**Main Research Variables:** Patients' experience with arm care and exercise advice after breast cancer surgery.

**Findings:** Topics raised by respondents included perceptions of inadequate and conflicting advice, lack of acknowledgment of women's concerns about upper limb impairments, an unsupported search for information about upper limb impairments, fear of lymphedema, women's demand for follow-up physiotherapy, and some positive experiences with supportive care.

**Conclusions:** Upper limb impairments are problematic for some breast cancer survivors, and these concerns are not always taken seriously by health professionals. To date, standardized advice is provided that does not meet the needs and expectations of a cohort of women after breast cancer surgery.

**Implications for Nursing:** Health professionals could better address patients' concerns about upper limb impairments by providing accurate advice relevant to the surgery.

ers) refers to perceived threat as the sum of how at risk an individual feels about the health risk in question (perceived vulnerability) and how severe an individual perceives the health risk to be (perceived severity). Perceived coping refers to how confident an individual feels to carry out instructions as advised (self-efficacy) and how effective the individual perceives the advice to be (response efficacy). The combination of these factors may aid exploration about how women internally

negotiate compliance with advice about arm care and exercise after breast cancer surgery.

The authors conducted a survey to examine women's perceptions toward advice given about arm care and exercise after breast cancer surgery. Specifically, the survey was aimed to explore factors that contributed to women's intention to avoid strenuous arm activity from 6–15 months after breast cancer surgery (Lee et al., 2009). Based on women's categorical responses to specific survey questions, the authors found that the two strongest contributing factors were fear of lymphedema and receipt of any arm care advice. This companion article aims to offer additional insight into women's experiences and feelings on advice received about arm care and exercise by analyzing comments volunteered by women who answered an open-ended question about their upper limb recovery. Free-text comments obtained from responses to open-ended questions are valuable in understanding and illustrating survey responses (Garcia, Evans, & Reshaw, 2004; Marcinowicz, Chlabicz, & Grebowski, 2007). However, women who volunteer comments are likely to have more time available or to be outliers with strong opinions or extreme experiences (Garcia et al., 2004). The experiences usually are negative but may include positive responses (Garcia et al., 2004). As a result, this exploratory article describes treatment issues that concern women in this population but were not identified via the quantitative survey analysis so that a full spectrum of experiences can be realized.

## Methods

The development of the survey used for the current study has been described previously by Lee, Kilbreath, Sullivan, Refshauge, and Beith (2007). The survey consists of 45 items relating to demographic characteristics, information about the cancer and treatment received, presence and type of arm or chest symptoms, arm function, advice received about arm care and exercise, fear of developing lymphedema, and intention to protect the affected arm. The findings were presented by Lee et al. (2009), and the survey can be viewed at [www.fhs.usyd.edu.au/physiotherapy/pdf/post\\_bc\\_survey8.pdf](http://www.fhs.usyd.edu.au/physiotherapy/pdf/post_bc_survey8.pdf). The current report describes the responses to the optional question: "Do you have any comments you would like to make about your experience as a patient and arm care or exercise advice given after your breast cancer intervention?" The open-ended question was the last question in the survey; all other questions in the survey were closed-ended, except for another open-ended question that asked women to describe any issues with arm function. The authors did not expect the open-ended question to attract many responses because they believed that the survey was comprehensive based on pilot testing. The open-ended question was added to ensure that the questionnaire was comprehensive for all respondents and provided an opportunity

for them to comment on any issues that they believed were not covered adequately by the other items. The comments are likely to have high validity given that they were volunteered, as opposed to responses to focused, closed-ended questions. The authors do not claim that the responses are reliable, but they are likely to represent a group of patients with strongly held views.

## Recruitment

Following approval by participating institutions' ethics committees, 180 eligible patients were recruited to complete the survey in the outpatient setting of three cancer treatment sites. Inclusion criteria were women who had undergone surgery for early breast cancer in the past 6–15 months without recurrence who could read and comprehend English. Treatment sites included two public hospitals in inner Sydney, Australia, and a private hospital in suburban Sydney, ensuring a mix of public and private patients. The postoperative time interval was selected because women were likely to have completed adjuvant treatment and returned to normal activities, such as employment, following their breast cancer treatment within this period. Consenting participants were asked to complete the survey in the waiting room. A postage-paid envelope was provided to respondents who did not complete the survey in the waiting room. No identifying information was recorded about respondents.

## Respondents

The response rate to the survey was very high, with 175 of 180 questionnaires (97%) returned by patients in the waiting room ( $n = 114$ ) or by mail ( $n = 61$ ). Of the 175 surveys returned, 48 women (27%) responded to the open-ended question about their experience with advice about arm care and exercise. Most women in the comments group were college educated; had undergone mastectomy, axillary lymph node dissection (ALND), and chemotherapy; and were symptomatic in their upper limb or chest (see Table 1). No differences were found between respondents to the open-ended question and nonrespondents in age, body mass index, employment status, time since surgery, dominance of affected arm, or treatment with radiotherapy.

## Data Analysis

Responses were reviewed and initially categorized by the first author. The categorization was reviewed and refined by all authors in discussion. Responses were grouped according to topic; resultant categories and each entry therein were reviewed subsequently. Categories were focused or expanded to reflect common issues raised by respondents (Babbie, 2004). Frequency of responses in each category or topic is reported in the Results section. Responses that did not fit into any topic were grouped as "other responses." The respondents

**Table 1. Sample Characteristics**

Characteristic	Comments (N = 48) <sup>a</sup>		Total (N = 175) <sup>b</sup>	
	$\bar{X}$	SD	$\bar{X}$	SD
Body mass index (kg/m <sup>2</sup> )	25.97	5.38	25.37	4.64
Time since surgery (months)	10.56	2.97	10.31	0.22
Characteristic	n	%	n	%
<b>Age (years)</b>				
Younger than 50	17	35	63	36
50–59	18	38	57	33
Older than 60	13	27	52	30
Missing	–	–	3	2
<b>Employed</b>	32	67	111	63
<b>College educated</b>	38	80*	106	61
<b>Hospital site</b>				
1	12	25	54	31
2	16	33	58	33
3	20	42	63	36
<b>Affected arm dominant</b>	21	44	89	51
<b>Type of cancer surgery</b>				
Lumpectomy	13	27*	92	53
Mastectomy	33	69*	79	45
Other	–	–	2	1
Unknown or missing	2	4	2	1
<b>Extent of axillary surgery</b>				
None or SLNB	16	33*	106	60
ALND	31	65*	66	38
Unknown	1	2	3	2
<b>Treatment</b>				
Chemotherapy	38	79*	112	64
Radiotherapy	31	65	124	71
<b>Symptoms present in arm or chest</b>	23	48	62	35

\*p &lt; 0.05

<sup>a</sup> Subgroup that responded to the open-ended question<sup>b</sup> All respondents to the original survey

ALND—axillary lymph node dissection; SLNB—sentinel lymph node biopsy

Note. Because of rounding, not all percentages total 100.

to each topic were compared to the subgroup of survey respondents who answered the open-ended question and to all respondents of the original survey for demographic and treatment variables and the presence of symptoms.

## Results

Women's comments were focused on dissatisfaction with advice received about exercise and arm impairments, care, and use. The 48 comments involved inadequate advice about arm care and exercise, conflicting advice about use of the affected arm, health professionals' lack of acknowledgment of arm issues, individuals' perception of unsupported search for information, women's demand for follow-up physiotherapy, fear of lymphedema, and positive comments received

from health professionals and health organizations on supportive care. The results are presented in order of response frequency to describe the experiences of the respondents. Typical comments in each category are included to illustrate each point.

### Inadequate Advice About Arm Care and Exercise

Respondents frequently commented on lacking or delayed advice and the absence of follow-up after surgery. Most of the 23 respondents in this group were younger than the average age of the comments and total groups.

Exercise and advice was certainly not part of the routine treatment.

*Case B24, 15 months after mastectomy, ALND, chemotherapy and radiotherapy on dominant side, aged 40–49 years*

I was given no advice as to when to start exercising after surgery, hence I did not start exercise for about five weeks! In fact, not much advice [was] given about exercise at all!

*Case B2, eight months after lumpectomy, ALND, chemotherapy and radiotherapy on nondominant side, aged 40–49 years*

I was given very little information about arm care following surgery—just a few brochures.

*Case B53, 13 months after lumpectomy, sentinel lymph node biopsy (SLNB), radiotherapy on dominant side, aged 40–49 years*

Post-op physio exercises were very “mild” and [there was] no recommendation for follow-up physio or advice.

*Case A17, six months after lumpectomy, ALND, chemotherapy and radiotherapy on nondominant side, aged 40–49 years*

### Conflicting Advice About Use of Affected Arm

Twelve respondents had some confusion about advice received concerning arm care and exercise after breast cancer treatment. Some women emphasized inconsistencies in the advice they received and the consequent confusion in their interpretation of conflicting advice. No differences were observed in demographic or treatment variables or presence of symptoms among the topic respondents and the comments and total groups.

I was given very conflicting advice on the day of discharge from hospital for removal of lymph nodes. Nursing staff insisted I rest the arm completely (i.e., I was told not to even use it to make a cup of tea) for at least the period of time I had the drain in (about

two weeks). Doctor also came in that morning and his words were, "Whatever you do, don't carry your arm like a broken wing—use it as much as you can." Very confusing. I am so glad I took his advice and am proud of the usage I have of my arm.

*Case A20, nine months after mastectomy, reconstruction, unknown axillary surgery, chemotherapy and radiotherapy on dominant side, aged 60–69 years*

It seems I have received confused messages about arm care. Pamphlets say don't lift anything heavy, others say build up to lifting heavier things.

*Case B5, seven months after mastectomy, SLNB, chemotherapy and radiotherapy on dominant side, aged 50–59 years*

## Women's Demand for Physiotherapy

Seven women who requested physiotherapy were symptomatic at the time of survey administration, and all 10 women who raised this issue underwent chemotherapy. A typical comment was as follows.

I think an eight-week course with a hospital physio would be a fabulous idea after surgery. In that time you are unsure of what you are supposed to be doing or *not doing* and I would have found this extra service a great benefit.

*Case C16, six months after mastectomy, SLNB, chemotherapy and radiotherapy on dominant side, aged 40–49 years*

## Health Professionals' Lack of Acknowledgment of Arm Problems

Ten women who volunteered comments about health professionals' lack of acknowledgment of arm problems had undergone ALND and were genuinely at risk for developing impairment. Seven reported shoulder restriction and arm swelling, and one woman reported arm swelling only. Comments identified medical specialists, doctors in general, and physiotherapists as the sources of the issue.

I feel both my surgeon and oncologist were somewhat dismissive of my chances of developing arm swelling or other arm problems.

*Case A11, 15 months after mastectomy, ALND, chemotherapy and radiotherapy on dominant side, aged 50–59 years*

I was treated like I was paranoid of my arm swelling.

*Case B24, 15 months after mastectomy, ALND, chemotherapy and radiotherapy on dominant side, aged 40–49 years*

Some women expressed concern and frustration with health professionals who were not eager to refer them for treatment.

I had to badger to get a physiotherapist to see me after my movements were obviously restricted at 20 days post-op.

*Case C22, six months after mastectomy, ALND, chemotherapy and radiotherapy on dominant side, aged 40–49 years*

I don't believe that enough interest is taken in how the arm is responding to the surgery. Unless there is a definite problem with a high degree of severity, any general discomfort is ignored, probably because it is not really debilitating and no one knows how to help.

*Case C20, 14 months after mastectomy, ALND, chemotherapy on dominant side, aged 40–49 years*

## Unsupported Search for Information

Six women reported that they actively searched for information about arm problems and lymphedema. They expressed anger at the failure of the health system to provide them with arm care and exercise information and the subsequent need to search for their own information. All women who raised this issue were symptomatic and were college educated.

I had to find the advice and professionals. Very confusing and frustrating!

*Case A17, six months after lumpectomy, ALND, chemotherapy and radiotherapy on nondominant side, aged 40–49 years*

I felt very much that unless I actively sought answers and did research and follow-up, I would continue to be very vulnerable, uninformed, and anxious. I found that there is a lot of information and support available but a patient needs to have a strong sense of their [right] to that information, be able to formulate the right questions and have good research skills to access it and be confident enough to keep asking—this is not easy at a time when one feels vulnerable and fragile.

*Case B41, 15 months after lumpectomy, ALND, chemotherapy and radiotherapy on nondominant side, aged 50–59 years*

## Supportive Care

Five responses involved supportive care. Some women commented favorably on the help they received from health professionals and organizations in relation to manual lymphatic drainage, stretching exercises, and information about activities to avoid. In contrast to women who volunteered negative comments, women who volunteered positive comments about supportive care did not offer in-depth reviews of their experiences. No other differences were found in demographic variables, treatment variables, or the

presence of symptoms between women who made positive or negative comments. The following comments identified the supportive help received from physiotherapists and a breast cancer nurse.

I am convinced that the physiotherapists' exercises were very beneficial. Had I not had access to this resource, who knows how more prolonged the discomfort would have been.

*Case B9, nine months after lumpectomy, ALND, chemotherapy and radiotherapy on nondominant side, aged 60–69 years*

Breast cancer nurse helped me tremendously. She has made my life more bearable.

*Case A1, seven months after mastectomy, reconstruction using the rectus flap, ALND, chemotherapy and radiotherapy on non-dominant side, aged 50–59 years*

Other comments not reproduced in this article referred to positive experiences with occupational therapists and the Cancer Council, a nongovernment Australian organization that advocates for the rights of patients with cancer to the best available treatment and supportive care.

## Fear of Lymphedema

Two women said that their fear of lymphedema was very powerful. One woman reported that lack of knowledge and psychological preparation for lymphedema intensified her fear, whereas another woman commented that the information she received was overly alarming. The women appeared to be worried about lymphedema, despite reassurance from health professionals. All three women who raised the issue were college educated, were employed, and had undergone radiotherapy. One respondent underwent ALND, and two underwent SLNB. Their comments included the following.

I think I have a mild case of lymphedema so I am going to a breast care nurse to get arm care advice! My radiotherapist doctor referred me as I was concerned. She says it's very mild but I am still worried.

*Case B58, seven months after mastectomy, SLNB, chemotherapy and radiotherapy on dominant side, aged 50–59 years*

I had to push for treatment for arm swelling. I also found that once I received treatment, some of it was a little over the top. I felt much more alarmed than I probably needed to be. So overall it was a bit of a roller-coaster when really I should have received practical sensible advice from the beginning.

*Case B24, 15 months after mastectomy, ALND, chemotherapy and radiotherapy on dominant side, aged 40–49 years*

## Discussion

Overall, the current study outlined the views of presumed outliers who mostly expressed dissatisfaction about their experience receiving advice about arm care and exercise after breast cancer. The small sample of respondents to the open-ended question consisted primarily of women who underwent mastectomy, ALND, and chemotherapy; were college educated; and were symptomatic in their arm or chest. Mastectomy, ALND, and chemotherapy are recommended commonly for women with invasive breast disease (Australian Safety and Efficacy Register for New Interventional Procedures—Surgery, 2005). These women are at high risk for upper limb impairment (Peintinger, Reitsamer, Stranzl, & Ralph, 2003; Sugden, Rezvani, Harrison, & Hughes, 1998) and also are likely to be symptomatic in their affected arm or chest. Their increased exposure and experience receiving advice about arm care and exercise may have increased their response rate. In addition, college-educated women may be more accustomed to communicating their ideas and opinions in writing (Garcia et al., 2004; Garcia, Reshaw, Fitzsimons, & Keene, 1998; Jackson & Furnham, 2000) and, therefore, more likely to offer comments in the survey than women who were not college educated.

Although the survey achieved a high response rate, the response rate for the open-ended question was low and the frequency of negative comments was high. The result is consistent with other studies that have used open-ended questions in surveys (Bankauskaite & Saarelma, 2003; Garcia et al., 1998, 2004; Jackson & Furnham, 2000; Marcinowicz et al., 2007; Parkhouse, 1991). Respondents likely had no need to make additional comments because the survey questions covered their experiences comprehensively. Twenty-five percent of respondents felt that their concerns had not been addressed adequately in the course of their treatment and offered suggestions for better care, illustrating the current study's value in providing additional information about an important population of women who have experienced breast cancer.

The current study's results generally are consistent with Protection Motivation Theory (Rogers, 1983). Fear of lymphedema was mentioned by some respondents and is a manifestation of the components of perceived vulnerability and perceived severity. Inadequate advice and conflicting advice were mentioned by many respondents; these categories align with the coping mechanism of perceived response efficacy. Women's demand for physiotherapy was mentioned by 25% of the respondents and aligns with the coping mechanism of perceived self-efficacy. Of interest, few comments align with the perceived threat component of the theory. The emphasis was on coping mechanisms, but three other categories that did not fit the concepts of the Protection Motivation Theory emerged; lack of acknowledgment, unsupported

search for information, and supportive care are external to self-efficacy and may even undermine it. Healthcare professionals should be sensitive to women's efforts to overcome the disease and support women's need to control their health outcomes as much as possible. The results indicate that Protection Motivation Theory may be too focused on individual responses and could be improved by considering external and supportive factors.

Five of 23 women who commented about inadequate advice probably did not receive advice because they had very few lymph nodes removed and were at low risk for upper limb impairment. All other women who commented underwent ALND and should have received some form of arm care or exercise advice. However, other explanations may exist for their perceptions of inadequate advice. Women may have had poor recollection of advice because of difficulties comprehending and retaining information in the immediate period after surgery (Dunn et al., 1993). Understandably, women experience considerable stress from a cancer diagnosis and recent surgery; as a result, women may perceive advice to be inadequate, regardless of its adequacy (Ardern-Jones, Kenen, & Eeles, 2005; Dunn et al.; Hallowell, Green, Statham, Murton, & Richards, 1997). Some women's perception of the adequacy of advice also may be dependent on their interpretation of the means by which advice is delivered. For example, one woman (B53) did not interpret brochures as an adequate form of advice. The authors inferred that this woman believed that advice about arm care and exercise should be individualized by healthcare professionals. This opinion is supported by literature that recommends one-on-one consultations, particularly in the instruction of exercise, because it allows information to be tailored for the individual and the opportunity for questions and feedback (Reo & Mercer, 2004; Rice & Johnson, 1984).

The current study's findings confirm that some women receive conflicting information about the extent to which they may use their arm after surgery, with some advice informing women to avoid strenuous arm activity and other advice encouraging the opposite. Understandably, many women are confused and frustrated by this conflicting information. Current evidence does not support an association between strenuous arm activity and the development of lymphedema (Ahmed et al., 2006; Cheema, Gaul, Lane, & Fiatarone Singh, 2008; Kilbreath et al., 2006; McKenzie & Kalda, 2003); therefore, women should be encouraged to exercise the arm and use it as normal to regain range and strength during recovery. The result indicates that healthcare professionals should update their advice so that women receive consistent and accurate information about arm use after surgery.

Generalized information is helpful and efficient in addressing the overall needs of breast cancer survivors. However, differences in demographic and treatment variables and internal perceptions of health threat and coping behavior prevent generalized information from

satisfying individual needs. One way to increase information specificity and patient satisfaction is to tailor the information for type of surgery to address differences in risk of impairments. This means that information about lymphedema, shoulder restriction, and risk-reduction strategies should be targeted to women at high risk for developing the impairments (i.e., women who have undergone ALND or mastectomy).

The women who perceived a lack of acknowledgment of arm problems by health professionals all had undergone ALND, placing them at risk for upper limb impairment. Most also were symptomatic at the time of survey administration; therefore, their concerns about upper limb impairments would appear to be reasonable and justified. The dismissive attitude displayed by some healthcare professionals toward impairment reported by the women has been raised previously in studies of breast cancer survivors who had lymphedema (Carter, 1997; Collins et al., 2004; Greenslade & House, 2006). The current study's results are interesting because a wealth of information is provided to women about lymphedema and risk-reduction strategies, but when women present with arm swelling, their symptoms are disregarded.

Reasons why some healthcare professionals are dismissive of arm swelling when women present with the condition are unclear. A possible explanation is a lack of knowledge about what can be done to manage lymphedema and to whom professionals should refer patients. Lymphedema, unlike cancer, is not a life-threatening condition and healthcare professionals divert focus from discussing the condition to the treatment of the cancer itself. Healthcare professionals also may perceive women's symptoms to be mild and, therefore, not problematic. Lastly, professionals may be reluctant to refer patients for treatment because of the paucity of quality evidence on the effectiveness of lymphedema treatment (Kligman, Wong, Johnston, & Laetsch, 2004; Moseley, Carati, & Piller, 2007).

## Conclusion

Some breast cancer survivors perceive that health professionals do not address the possibility or presence of upper limb impairments adequately. Individualized information tailored for type of surgery and based on current evidence is recommended.

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